



4140-01-P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

The National Institutes of Health “Methods and Measurement in Sexual & Gender Minority Health Research: Identifying Research Opportunities”

ACTION: Request for Comments.

SUMMARY: Sexual and gender minority (SGM) is an umbrella phrase that encompasses lesbian, gay, bisexual, and transgender populations as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional, societal, cultural, or physiological norms. This includes Disorders or Differences in Sex Development (DSD), sometimes known as intersex.

The Sexual & Gender Minority Research Office (SGMRO) at the National Institutes of Health (NIH) has developed the document “Methods and Measurement in Sexual & Gender Minority Health Research: Identifying Research Opportunities” pertaining specifically and exclusively to methods and measurement research in SGM health research. Experts in the field identified research opportunities related to methods and measurement in SGM health research during a workshop held in the Spring of 2018. The document reflects the content of the discussion among participants at the Methods and Measurement in SGM Health Research Workshop and does not represent an official position of NIH or any other government agency. We would like to obtain comment on the specifics of this document to consider for the purposes of informing and enhancing its content.

DATES: To ensure consideration of your comments, responses must be received by
[INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER].

ADDRESSES: Responses to this notice must be submitted electronically by email to sgmhealthresearch@od.nih.gov. Please use the subject “Comments: Measurement.”

FOR FURTHER INFORMATION CONTACT: Dr. Karen Parker, Division of Program Coordination, Planning, and Strategic Initiatives, Office of the Director, NIH, Building 1, Room 257, 1 Center Drive, Bethesda, MD, 20892, Telephone: 301-451-2055, Email: karen.parker@nih.gov.

SUPPLEMENTARY INFORMATION:

Background

In 2015, the National Institutes of Health (NIH) established the Sexual & Gender Minority Research Office (SGMRO) in the Division of Program Coordination, Planning, and Strategic Initiatives in the Office of the Director. The role of the SGMRO is to: coordinate sexual and gender minority (SGM) health research activities across NIH; represent NIH at conferences and events on trans-NIH activities focused on SGM research; coordinate and convene conferences and workshops to inform priority setting and research activities; collaborate with NIH Institutes and Centers on the development of SGM health research reports; manage information dissemination related to SGM research; and work with NIH Institutes and Centers to leverage resources and develop initiatives to support SGM health research.

The *21st Century Cures Act*, signed into law on December 13, 2016, included SGM-specific provisions, by amending the Public Health Service Act, SEC. 404N. [283] POPULATION FOCUSED RESEARCH. Those provisions are summarized as follows:

“The Director of the National Institutes of Health shall, as appropriate, encourage efforts to improve research related to the health of sexual and gender minority populations, including by: facilitating increased participation of sexual and gender minority populations in clinical research supported by the National Institutes of Health, and reporting on such participation, as applicable; facilitating the development of valid and reliable methods for research relevant to sexual and gender minority populations; and addressing methodological challenges.”

As a result of the growing need to develop better measures and methods to accurately capture and understand the health of SGM populations, the SGMRO hosted a workshop to identify research opportunities in methods and measurement in SGM-related health research. The planning committee included both NIH staff and extramural researchers who designed the workshop agenda and developed a schema to guide the discussions.

The workshop focused on three areas: measurement of SGM status; measurement of related constructs; and sampling. Extramural researchers were invited who represented various research areas, stages of career, populations of interest, and disciplines.

Community members, NIH staff, and other federal staff were also included. Discussions focused around varying concepts to consider under each of the domains identified by the planning committee; overarching themes of intersectionality, lifespan,

culture, and historical context and cohort effects were considered throughout the discussions. The concepts for consideration are highlighted below:

I. Measurement of SGM Status

- o Sexual Orientation (identity, behavior, attraction)
- o Gender Identity (cisgender, transgender, gender nonconforming, non-binary)
- o Disorders or Differences of Sex Development/Intersex (medical condition at birth vs. self-identified)
- o Fluidity (identity across contexts, time, and developmental stage)
- o Assessment Modality (survey, report, collection from a provider, on the phone, internet, paper)
- o Clinical Settings

II. Measurement of Related Constructs

- o Stigma (structural, interpersonal, individual or internalized)
- o Coming Out/Disclosure Process
- o Family Relationships
- o Cultural Competence/Humility in the Healthcare and Research Settings (providers, facilities, etc.)

III. Sampling

- o Probability vs. Non-Probability Sampling
- o Sampling Across Demographics/Sub-populations
- o Small Sample Sizes

Information Requested

This notice invites public comment on the proposed research needs and opportunities developed at the Methods and Measurement in Sexual and Gender Minority Health Research Workshop. To inform the final document, comment is requested on the following questions:

- 1) What are the most important and relevant methods and measurement-related research questions to members of the SGM community?
- 2) What are the key methods and measurement-related research questions missing from the research opportunities that should be included?

Comments regarding this information collection are best assured of having their full effect if received within 30 days of the date of this publication. [INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER].

General Information

All of the following fields in the response are optional and voluntary. Any personal identifiers will be removed when responses are compiled. Proprietary, classified, confidential, or sensitive information should not be included in your response. This notice is for planning purposes only and is not a solicitation for applications or an obligation on the part of the United States (U.S.) government to provide support for any ideas identified in response to it. Please note that the U.S. government will not pay for the preparation of any comment submitted or for its use of that comment.

Please indicate if you are one of the following: grantee or other PI, administrator, student, institutional leader or institutional administrator, NIH employee, or other. If you are an investigator, please indicate your career level and main area of research interest, including whether the focus is clinical or basic. If you are a member of a particular

advocacy or professional organization, please indicate the name and primary focus of the organization (e.g., research support, patient care, etc.) and whether you are responding on behalf of your organization (if yes, please indicate your position within the organization). Please provide your name and email address.

Privacy Act Notification Statement: We are requesting your comments for Methods and Measurement in Sexual & Gender Minority Health Research: Developing a Research Agenda and Identifying Research Opportunities

(https://dpcpsi.nih.gov/sites/default/files/MethodsMeasures_Paper_508_FV.pdf). The information you provide may be disclosed to NIH senior staff and those serving on the SGM Research Coordinating Committee and to contractors working on our behalf.

Submission of this information is voluntary. However, the information you provide will help to categorize responses by scientific area of expertise, organizational entity or professional affiliation.

Collection of this information is authorized under 42 U.S.C. 203, 241, 2891-1 and 44 U.S.C. 310 I and Section 301 and 493 of the Public Health Service Act regarding the establishment of the National Institutes of Health, its general authority to conduct and fund research and to provide training assistance, and its general authority to maintain records in connection with these and its other functions.

Dated: March 8, 2019.

Lawrence A. Tabak,

Deputy Director,

National Institutes of Health.

[FR Doc. 2019-04790 Filed: 3/14/2019 8:45 am; Publication Date: 3/15/2019]